

CRS PARENT CONNECTION

Alabama Department of Rehabilitation Services



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CRS Parent Consultant, Linda Foster

Hello, I am Linda Foster, parent consultant with Children's Rehabilitation Service in Andalusia. I have been employed by CRS three years, one of which was spent serving on active duty in Operation Enduring Freedom at Ft. Benning, GA. After 25 years of my adventurous military career, I retired this past May.

My daughter, Justus, captured the delight of my life when

she pranced into being July 27, 1994. Born with a right sided heart (dextra cardia diagnosis), pulmonary atresia and asplenia, Justus had her first surgery at age one month and her second surgery at age five months. With guidance from the Crenshaw County Health Department, we enrolled in the CRS heart program in 2000. Justus had her third surgery at eight years of age in San Francisco, CA where on the second day following surgery, her exhausted lungs collapsed, causing triple cardiac arrest. My angel died October 11, 2002. With my world shattered, heart broken and faith in God, I am on the road to recovery one day at a time. I carry my angel

in my heart daily. I thank Lainie Hilburn for the book, "Grace for Grief" and highly recommend it for grieving parents. I would like to share with you a poem I wrote in my daughter's honor. It is entitled "That Angel of Mine." (Please see Linda's poem on page 10 of this newsletter.)

The importance of a support system is tremendous. I know I have a ways to go, but I have gained strength and courage



Linda receives a welcome back from her fellow CRS parent consultants.

in my struggle to persevere in serving CRS families. I believe that aiding and assisting families is the basis to being a parent consultant. As mothers of children with special needs, CRS parent consultants see and feel with you, experience being our greatest teacher. The most rewarding part of this job is meeting the families, finding solutions, giving a helping hand and lending an

understanding ear. The one thing we have in common drives us to foster support, network, and to seek and reach. As a parent consultant, I am committed to advocate, to listen, to find resources and support as well as stand with and for our families. I attend IEP meetings and make home visits. I am a member of the Individual, Family and Support Counsel (IFSC), a 2010 workgroup and just a down to earth friend that will have lunch or listen at any time. I value my position with CRS, being fortunate to work with caring people, receive training and attend conferences that equip me with knowledge and information that will benefit families.

The Andalusia CRS office will soon be moving to a new location at 1082

Village Square Dr., Suite 2. We are very excited to be able to better accommodate our families with more clinic space, a family resource center and other much need accessibilities. I would be delighted to talk or visit with our families. You may call me at 334-222-5558 or 1-800-723-8064, or contact me by email at lsfoster@rehab.state.al.us.

Linda Foster, CRS Parent Consultant

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CRS PARENT CONNECTION

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Parent Connection is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

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From The Director's Chair



Hello, Everyone!

I am excited that fall – my favorite time of year – is finally here! The long hot summer is over and cooler temperatures are on the way. The colors of the season and the holiday festivities are something I look forward to each year and, oh yeah, FOOTBALL IS BACK!

On a serious note, I need to mention that the continuing effects of the last few years of reduced state and federal funding, along with the ever-rising costs of services and operating expenses (rent, utilities, gasoline, supplies, equipment, employee health insurance) are presenting CRS with great challenges. To make matters worse, we are no longer able to supplement our state and federal budgets to keep all services at current levels for our families. Because of this, we will be forced to take steps to reduce costs in several areas in the coming year.

It is important for you to know that we believe it is vital that we maintain the level of clinic services currently available to families. Our clinical medical and clinical evaluation services are our first priority. In an effort to continue providing these services at present levels, we have developed a budget for next year that reduces our expenditures for supplies, in-state travel, out-of-state travel, equipment, repairs and maintenance as well as statewide staff. Each of these budget items has been reduced to the lowest possible level.

The Alabama Department of Rehabilitation Services will keep communication lines open to you! Please be assured that, as always, we will make every effort to be efficient with the funds we have and try to and find additional funding from any source that we can in order to provide quality services.

We will keep you informed about our funding situation and also inform you of any ways that you might provide assistance to help us maintain services to you and to all our families.

> Until we talk again! Cary Boswell, Assistant Commissioner

Plan Ahead for Your Child's Medicine at School

September is a month of hope and promise for children with disabilities. The school year is off to a new start, and parents and children alike are full of expectation that this will be a good year. A major area of importance that is sometimes overlooked in the frenzy to become organized for school is how to plan the child's medicine regimen for the school day.

Many children take prescription medication at school. A bit of careful planning at the beginning of the school year can help parents track their child's medicine use at school and let them know when supplies are low. Running out of medicine can create all types of problems for children and their teachers. For some children it can affect their ability to sit and listen; for others it can have a major affect on health.



The following tips are to help parents ensure that their child's medicines are taken properly and safely, to prevent lapses in medication use, and to minimize the opportunity for misuse or abuse by others.

- Contact the school nurse to let her or him know that your child will need medicine at school. Find out the school's policies on giving prescription medication to students and who will be in charge of giving your child the medicine.
- 2. Schools require written permission from you and your child's doctor to give your child medicine. Be sure you obtain a copy of the permission form from the school, sign it, and have your child's doctor sign it, too.
- 3. Be sure to bring the medicine in its original container. Ask the pharmacy or your child's doctor for an extra prescription bottle for school use, if you need one. The bottle should list the name of the medicine, the name of the doctor, the dosage, the

- time of day it is to be given, and the way in which it is to be given.
- 4. Count the number of tablets you take to school, and have the school nurse or other responsible school person do a recount in your presence. Ask the school to maintain a log of the date and the amount of medicine you brought to school. It is important to list the strength of each dose as well.
- 5. Ask that the person who gives your child medicine at school make sure that the child actually swallows it while the adult watches. Some children avoid taking their medicine, and it may fall into the hands of other children.
- 6. Ask that the nurse verify the identity of your child each time before giving the medicine.
- 7. Teach your child to check his or her medicine each time before taking it. Help the child to understand the responsibility for taking medicine correctly. Schools are busy places, and it is not unheard of for a child to be given the wrong prescription accidentally.
- 8. If your child needs to have the school medicine supply at home over a holiday, ask the nurse to verify, in your presence, the quantity of medicine you are taking home with you. This is a normal precaution that parents should take with all medicines that are given at school.
- 9. Discuss with the school nurse the type of medicine your child is taking and any potential side effects of which the nurse or other school staff, including your child's teachers, should be aware.
- 10. If your child has complex medical issues or requires multiple medications or procedures in school, make sure your child has a written health plan for school and a written emergency plan. For more information about health and emergency plans, talk with the school nurse and your child's doctor. To see a sample health plan, go to PACER Center's Health Center Web site: www.pacer.org/health/index.htm

By Dixie Jordan and Carolyn Allshouse Pacesetter; Fall, 2003; PACER Center, Inc.; Minneapolis, MN

FAMILY VOICES



Bright Futures is a vision of children's healthcare. It offers health professionals a practical approach to health care for children from birth through adolescence. Family Voices has collaborated in

developing Bright Futures for Families materials, including a website, www.brightfuturesforfamilies.org, to help families promote and improve the health and well-being of children of all ages, including their children who have special health care needs. These materials mesh with the materials and concepts developed for professionals, thus further encouraging partnerships to grow and flourish.

One example of the Bright Futures for Families materials is the Health Care Visit Check List. A child's health visit is a key time for families and health care providers to share information and observations about the child's development. This checklist helps families prepare for health visits so they can develop a good relationship with their child's health care provider.

Choosing a Health Care Provider

If you have a choice, look for a provider whose style and office procedures fit your needs. Talk with family and friends about providers they recommend.

- ◆ Do you think his/her style fits your needs and those of your child?
- ◆ Can you talk easily with this provider? Is your language and culture understood and respected?
- ♦ Will this provider offer a "Medical Home?"
- ♦ Is the office location convenient?
- Are there hours or times you can call with questions?
- ♦ Who is available when the provider is away?
- Will your health insurance cover this provider?
- ◆ If you don't have health care coverage, call toll-free 1-877-KIDS-NOW for information on free or low-cost children's health insurance. Check with your health department, local hospital, or state chapter of the American Academy of Pediatrics.

Preparing for a Health Visit

- ♦ Think through the purpose of the visit (e.g. regular health check-up immunizations, illness, etc.) and bring along any records you'll need. Use the Bright Futures Family Pocket Guide or the Bright Futures Encounter Forms for Families to help you prepare. (Pocket Guides are available from CRS.)
- Think about your child's progress and what has changed since the last visit
- Make a list of questions or concerns you want to discuss.
 -Put worries into words. A good health care provider will try to help you think through issues and find answers or referrals.



- -Bring a notepad to jot down things you want to remember.
- -Are there concerns or updates from others who see your child, i.e. childcare center, school, sports, therapy program, hospital? -Prepare your child for the visit. Encourage your child to ask questions and discuss concerns. Bring a toy, art project, favorite book or homework to pass the time or to show the provider.

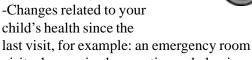
During the Visit

- Talk about what matters to you. Your way of seeing your child helps the health care provider understand more about your child's development and your priorities.
- ◆ Expect your child's health care provider to ask questions such as: "How does your baby respond to new people"? "How many hours does Juan sleep at night"? "How is school going for Tina"? "How does Philip handle stress"? "How are things going with Julia's therapy program"? "Kim, are you driving yet"?

(Continued on page 5.)

(Continued from page 4.)

- Ask questions about any things important to your child - getting along with others, playing sports, after school jobs, etc.
- Mention significant or interesting events that have occurred recently to share the unique nature of your child and family:



- visit; changes in sleep, eating or behavior patterns; alteration in seizure activity.
 -Family events that have happened since the last visit, i.e. a move, a new baby, death, divorce.
- ♦ Offer feedback about recommendations made to you about your child's health.
 - -Your opinions should be respected.
 - -Sharing information will strengthen the partnership, even if you don't always agree.
- Ask what's likely to happen next in your child's growth and progress and what you can do to support healthy development.
- Share ideas, observations, and good resources with your health care provider. In turn, ask for recommendations. Are there handouts, books or videos you can have or borrow?
- Give your health care providers constructive feedback on how they're doing caring for your child and providing information and support to you. Offer examples of suggestions that have been helpful.

After The Visit is Over, Ask Yourself

- ◆ Did you feel welcome and comfortable at the visit?
- Were there opportunities for you and your child to discuss concerns?
- ◆ Did your health care provider listen and communicate well?
 - -Did you understand everything discussed?
 - -If there was something you didn't understand, did you ask for and get a clearer explanation?
- ♦ If something unexpected or painful occurred, were you able to provide support for your child?

- ♦ If you didn't get to cover everything you had planned to discuss, is there an easy way to get answers to questions between visits (i.e. calling the office or a health line)?
 - -Are you comfortable waiting for the next visit?
 - -Are there other members of this provider team who can talk with you?
- If you didn't agree with your health care provider about an issue, did you discuss your concerns?
 Do you feel comfortable with the result?
- ♦ Were your values and views respected?

Joyful Tenacity Wins An Award For Daniel Orsag



Daniel Orsag, 19 years old from Mobile, was recently presented with the Alabama Rehabilitation Association/ Children's Rehabilitation Service (ARA/CRS) Achievement Award at the ARA annual meeting. Since his traumatic brain injury four years ago, Daniel's perseverance, family support and CRS assistance have assured Daniel of reaching his goals. The CRS team that has worked with Daniel was also recognized. The team members are Jo Blount, TBI care coordinator; Karen Bounds, R.N.; Pam Hutter, SLP; and Patti Fassbender, P.T.



From the Pen of the Youth Consultant

I am back again, and I have some exciting experiences to share with you! First, I had the chance to observe the CRS Teen Transition Clinic in Mobile during the month of July. The structure of this program is very amazing to me. The young person, parent/guardian and necessary specialists (independent living, recreation, etc.) all come together to brainstorm and make plans for the young person's future. A doctor's visit is included in this clinic as well. What I like most about this particular clinic is that it allows youth to be more included in making decisions about their health care. As of now, the CRS Teen Transition Clinic is only held at two sites—Birmingham and Mobile

Also in July, I traveled to Chicago, Illinois to attended my second board meeting with KASA (Kids As Self-Advocates). The meeting was very successful, and I must say that I learned more about disability culture and the disability movement itself. While in Chicago, KASA also participated in the 1st Annual Nationwide Disability Pride Parade. There were several different disabilities represented as we all joined together to show the pride we have for the disability community. On July 24-27, 2004 I traveled to Washington, D.C. I was selected to attend the 2004 National Youth Leadership Conference. One young person with a disability was selected from each state to represent his or her state. I got to meet and share ideas with other youth, meet adults who have been involved in the Disability Movement since the beginning, and voice my concerns with representatives from different government agencies. This was a great experience, and I encourage any youth who are interested to apply to participate in the conference next year.

Thanks for letting me share my experiences with you!

Jennifer Thomas, CRS State Youth Consultant

Youth Advisory Committee

The Youth Advisory Committee has really been moving along. The YAC used teleconference calls to communicate on a monthly basis during April, May and June. New members will be invited to the next YAC Retreat, which will take place in October. Keep looking out for more great things about the YAC.

2010 Transition Workgroup

2010 Goal 6 states, "All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life."

Three subgroups within the Transition Workgroup have been formed to help in working toward Goal 6.

Independence Subgroup: Promote independence as it relates to the individual by empowering children and youth with special health care needs to achieve life goals.

Employment Subgroup: Increase employment outcomes for youth with special health care needs.

Health Care Subgroup: Increase availability and access to all health care services needed as children become adults.

YLF News

Applications and brochures for YLF 2005 will be available soon. Look for more information on YLF in future newsletters or on the Alabama Department of Rehabilitation Services' website at www.rehab.state.al.us. If you or someone you know is interested in applying for YLF in June 2005, please let us know.

YAC... YAC... YAC...

Resources ☆ Resources ☆Resources☆

☆Do you want to learn more about the ADA (Americans with Disabilities Act)? Check out the ADA Game at www.adagame.org. This game is a fun way for people to learn more about the ADA and advocacy. The ADA Game is a free virtual game that is offered to anyone who wants to participate. Once you register, you will be assigned a city, then you and the other members of this city will work together to build an accessible community.

What's Happening

☆ On Saturday, September 18, 2004, Children's Rehabilitation Service hosted its very first Youth Forum, which was a part of the Needs Assessment process that takes place every five years. Forums such as this have been offered to the families of youth with special health care needs in the past. However, this time around CRS

decided to host a forum just for youth! A big thanks goes out to all of the youth who came to **SPEAK OUT** about the services they receive!

☆You weren't able to make it to the 2004 Youth Forum? Don't worry! You still have time to provide your input. As a part of the 2004 Needs Assessment, CRS is also administering the *Alabama Youth Survey* for youth with special healthcare needs ages 12-21. Please look for this survey in CRS offices across the state or give Jennifer Thomas or Linda Graham a call.

☆ The 15th Annual Alabama Transition Conference will take place March 7-9, 2005 in Auburn. The CRS Youth Advisory Committee presented at this conference in 2003 and did a fantastic job.

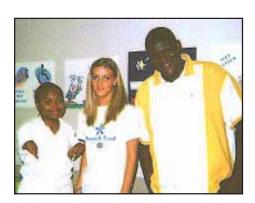
For more information about anything found in the *Let's YAC About It* section of this newsletter, please contact Jennifer Thomas, CRS State Youth Consultant, at jthomas@rehab.state.al.us or Linda Graham, State Adolescent Coordinator, at lgraham@rehab.state.al.us. You may also reach either of them at 1-800-441-7607.

Youth Power Workshops

This summer the CRS Youth Connection Program piloted two Youth Power Workshops. Youth from the Mobile and Gadsden areas were invited to come and learn more about self-determination and positive communication styles. The workshops proved to be successful, and as a result plans are being made to host Youth Power workshop in more areas throughout the state. Thank you to all the youth who participated in this event.



Mobile Youth Power Workshop, July 24, 2004



Gadsden Youth Power Workshop, July 20, 2004

Tips for Family Caregivers

Developed by: Anne Turner-Henson [UAB School of Nursing and LEAH] & Janet Johnston [UAB, PPC], UAB Birmingham, AL

Improving your own personal health can potentially enhance your ability to care for your child and possibly have a ripple effect on the overall health of the family. Remember healthy families are essential for children with chronic conditions to grow up and be productive adults.

- 1. Ask for help. Realize areas where others can help you and your family. Let others know of a specific need that could help reduce your load. Often church members, friends, neighbors, and family members would be glad to help with a specific task when asked. Explore options for respite care with your child's health provider (e.g., nurse, medical social worker).
- 2. Pay attention to the basics. Adequate sleep, eating



in moderation, a regular time for recreation and exercise can do a world of good in keeping the stresses manageable and in perspective. Take time for yourself. Avoid unhealthy behaviors to relieve stress/anger, (i.e. smoking, alcohol, fast driving, etc.) To prevent injury, learn good body mechanisms in lifting and carrying.

The old saying, "an ounce of prevention is worth a pound of cure" is true.

- **3. Stay connected.** Recognize your opportunities for friendships and support that are in the normal flow of your day (school, church, neighborhood, work activities) and develop outlets for you to show interest in others and opportunities for friendships to grow.
- **4. Prioritize and organize your time.** Decide what is reasonable to accomplish and set realistic expectations for your time. Look for ways to build in some extra time, (i.e. mail-order 3 month supplies of prescriptions and treatment supplies rather than a monthly trip to the drug store; look at your child's daily home treatment schedule, talk to your child's provider about how you can reduce the amount of time or complexity of your child's daily home treatments; prepare double amount of a meal when cooking and freeze the extra meal for a busy day, etc.).

- **5. Build your faith.** Studies have shown that spiritual strength makes a difference in coping skills and satisfaction in life.
- 6. Make your own personal health a top priority.

When scheduling your child's health appointments, schedule your own health check-up. When your child gets his/her annual vaccines, don't forget to get your yearly flu vaccine. Monitor your own health, (i.e. monthly breast self exams, pay



attention to your symptoms and seek early treatment rather than ignoring nagging symptoms). Avoiding or delaying treatment for physical or emotional problems (i.e. depression, anxiety in particular) will not make them "go away."

7. Stay flexible and adaptable. Even the best plans will need to be rearranged some days. Humor helps.

Medicaid's Non-Emergency Transportation Program

Submitted by the Alabama Medicaid Agency

The Medicaid Non-Emergency Transportation Program (NET) is set up to help cover the cost of transportation to and from a doctor's office, clinic or other place for medical care when fully covered Medicaid recipients have no other way to get to their appointments without obvious hardship. Medicaid issues vouchers for these medically necessary trips that can be planned ahead of time. This ride can be in a car, bus or van and can be provided by a friend, neighbor or family member. The recipient can also get a ride on a city bus or from other organized groups in their town or area. Medicaid should approve the request for NET vouchers before the trip.

To find out more about obtaining a voucher for a ride to medical appointments, interested parties may call 1-800-362-1504 (press 3 for a ride to a medical doctor or other medical appointment). The call is free.

Be An Effective Child Advocate

The American Academy of Pediatrics recently gave these guidelines on their website, www.aap.org, for becoming an effective child advocate.

- Choose your issue. Personal experience, community issues, and data on systemwide disparities are all sources of potential advocacy issues. Decide what it is you'd like to change.
- 2. Identify solutions. Prepare a list of possible ways to successfully resolve your issue.
- 3. Identify supporters. Chances are good that you're
 - not the only person or group advocating for an issue. Talk to parents and parent groups. Use the Internet to find other people or organizations that are working on related issues



and seek their assistance. Equally important is choosing a legislator or other government official who will sponsor and be a champion for your issue.

- 4. Develop a strategy. Will you advocate for change on the local, state, or federal level? Which of the three branches of government—executive, legislative, or judicial— is best positioned to help you achieve your desired outcome? Who will oppose your efforts and what can you do to neutralize the opposition?
- Frame you message. Work with someone who has experience in public or media relations to help develop and disseminate a clear, concise, and consistent message to help advance your issue.
- 6. Educate. Attend community, state and national organization meetings. Offer to be a speaker at a civic group or philanthropic organization or professional society event. Meet with lawmakers and other government officials. Write letters to your newspaper.
- 7. Mobilize supporters. Democracy is not a spectator sport! Establish and activate email alert systems

- and telephone trees to ensure that supporters make their lawmakers aware of the need and support for your initiative.
- 8. Testify. Offer to tell your story at a public hearing. The personal experiences of constituents are very powerful in convincing government officials to make changes.
- 9. Don't give up. Often times, it takes more than one attempt to enact a new law or implement a change in public policy. Take Thomas Jefferson's advice, "Eternal vigilance is the price of freedom."
- 10. Vote! Pay attention to what candidates are proposing for children...and make your decisions accordingly. Remember these are the people who will be making decisions about your issue. Take a child with you when you vote to teach them about this important civic duty!

Vote 2004

Voting is the foundation of our democracy and an important civil right; voting and political participation are essential privileges of community membership. The policies developed and implemented by those we elect impact us every day.

Power of the Disability Vote Campaign 2004 Judy Roy

Birmingham Independent Living Center 206 13th Street S.

Birmingham, AL 35233-1317 (205) 251-2223 ext. 102 bhamilc@bellsouth.net



Presidential Candidates

How do the candidates stand on disability issues? Two web sites are available to give you access to the platforms of the major candidates. They are www.nod.org and www.nod.org and www.aapd.com.

That Angel of Mine

Eight years ago, God (loaned) me an Angel! I prayed and prayed and she arrived somewhat dismangled. So precious, so sweet, all I hoped for. I truly thanked God, this Angel brought sheer joy, So sweet, so pure and delicately kind. "Yeah," she was spoiled, that Angel of mine. I knew this was an Angel loaned to me by God, She was so special, just look at how she trod. And those (thugs), Lolo, Tyrell & Ahmaud; They weren't that hard, they were Justus' bodyguards. She cherished the butterflies, for her they brought sheer delight, She'd sing and dance like them all through the night. Yes, I'm open to sign any autographs today, I'm the proud mother of an angel that flew away. She was proud that for my country I served, We honor those in uniform, the 383rd Army Reserve. She loved music and great presentations, She's honored to have singing, "The Latter Rain Generation." Thank you God for this Angel I raised, Our trials were many, but with us you stayed. I thank you Lord to have been chosen a special mother, It is a different kind of work, truly like no other. I salute all mothers of a special needs child, Keep on, press on, your job is merely classical style, It's a job you are chosen to do you see, Just an even closer walk with thee. I can not forget the day my Angel chose to go, You see that's when I left my heart in San Francisco. Be proud you knew her and hold her close, I had to let go, it was God who chose.

I will give autographs to those who want them signed, That Angel God loaned, just happened to be mine.





Written by: Mother, Linda Foster

(Linda's poem, written in honor of her daughter and included in Justus' obituary, was awarded the Shakespeare Trophies Head of Excellence from the World Famous Poets Society.)

Parents and Kids



Successful Homework

Let's face it, no one really likes to do homework and supervising your student can be a very stressful time of day for both of you. Try these ideas to help your student be successful at completing his/her assigned homework.

- Choose the time period that works best for your family and try to be as consistent as possible in setting this time aside as homework time.
- Provide a place that homework is to be done, whether it be at a desk or the kitchen table, be sure it is away from distractions. Make this your student's place to work each day.
- Go over the assignments and help your student make a plan of the order to accomplish them, check that the directions for each are clear. Determine the amount of time each assignment should take. Periodically check back to see how the student is progressing, and be available to assist if your student doesn't understand the work.
- ♦ If there is a lot of homework, plan for a ten-minute break every hour to stretch, get a snack or just chill out.
- When assignments are completed, briefly look them over to make sure your student has the basic understanding of the work. Above all be encouraging and use this time to maintain communication with your student about school and his/her work.

Help the witch break the code and reveal what ingredient she needs next.

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Out What's Ahead

November 2, 2004 Presidential Election—Go and Vote!

November 15-17, 2004 EI & Preschool Conference; Adams Mark Hotel; Mobile, AL; Parent stipends are avail-

able. Contact Jeri Hughes, 205-823-9226, JBH50@aol.com.

November 17-20, 2004 TASH Conference; Reno Hilton; Reno, Nevada; Contact: www.tash.org

January 27-29, 2005 Families USA Health Action 2005; Contact: www.familiesusa.org

February 21-23, 2005 International Conference on Patient and Family Centered Care; Fairmont Hotel; San Fran-

cisco, CA; Contact: www.familycenteredcare.org

March 13-16, 2005 NACHRI/N.A.C.H. Spring Conference "Creating Connections;" Fairmont Hotel; New

Orleans, LA; Contact: www.childrenshospitals.net